

A large, light purple, teardrop-shaped graphic on the left side of the page contains a wavy path in dark blue and gold. Three stylized human figures in blue and gold are positioned along this path: one at the top, one in the middle, and a group of three at the bottom.

# *Organizations That CARE:*

## *Case Studies of Excellence*

Anna T. Laszlo, M.A., Project Director

Laura B. Nickles, M.S., Associate Project Director

Sean M. Currigan, M.P.H., Research Associate

Abraham Feingold, Psy.D., Consultant

Sally Jue, M.S.W., Consultant



# *Table of Contents*



Acknowledgements .....	iii
Introduction and Purpose.....	v
The Case Studies	
Children's Diagnostic and Treatment Center Comprehensive Family AIDS Program Fort Lauderdale, Florida.....	1
The Core Center/Hektoen Institute Women and Children's HIV Program and Adolescent HIV Program Chicago, Illinois .....	9
Justice Resource Institute JRI Health Boston, Massachusetts .....	17
Metrolina AIDS Project Caring for Families Program Charlotte, North Carolina .....	25
University of California, San Diego Mother, Child, and Adolescent HIV Program San Diego, California.....	33
Appendixes	
Appendix A: On-Site Protocol .....	41
Appendix B: Discussion Guide for Ryan White Title IV Program Directors/Coordinators .....	43
Appendix C: Discussion Guide for Ryan White Title IV Consumer Staff.....	49



# Acknowledgments

This project could not have been possible without the support and contributions of many dedicated individuals. First, we thank Jose Rafael Morales, M.D., and Eda Valero-Figueira, Ph.D., HIV/AIDS Bureau (HAB), Health Resources and Services Administration. Their vision for this project both inspired and guided our work. We are grateful to the Title IV program directors/coordinators who participated in telephone discussions about the challenges and rewards of employing consumer staff members in their programs. Their insights led us to five programs that represent our case studies of excellence. These programs are:

- Children's Diagnostic and Treatment Center  
Comprehensive Family AIDS Program, Fort Lauderdale, Florida
- The Core Center/Hektoen Institute  
Women and Children's HIV Program and  
Adolescent HIV Program, Chicago, Illinois
- Justice Resource Institute  
JRI Health, Boston, Massachusetts
- Metrolina AIDS Project  
Caring for Families Program, Charlotte, North Carolina
- University of California, San Diego  
Mother, Child, and Adolescent HIV Program, San Diego,  
California.

We are indebted to the program directors and all the program staff members who generously gave their time and expertise during our on-site visits. Their willingness to honestly share the wealth of their experiences, the challenges they faced, and the lessons they have learned was invaluable. Most important, our deepest appreciation goes to the many consumer staff members who either participated in focus group meetings or telephone discussions. Their voices give credibility and reality to our work. Words of simple thanks seem inadequate for all the wisdom they shared with us.

We thank our project team: Sally Jue, M.S.W., Abraham Feingold, Psy.D., and Sean Currihan, M.P.H. Without them, this project would not have been so rewarding to complete.

Finally, we acknowledge the support of Caroline Watler, President, Circle Solutions, Inc., whose constant encouragement allows us to pursue work we not only truly love to do but which also makes a difference in the lives of people in our communities. We hope that *Organizations That CARE: Case Studies of Excellence* does just that!

Anna T. Laszlo, M.A., Project Director

Laura B. Nickles, M.S. Associate Project Director  
Circle Solutions, Inc.





# ***Introduction and Purpose***

From its origins as the Pediatric Demonstration Grants, the Title IV program of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has encouraged and supported grantees to involve consumers at all levels of program development and implementation. The HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) has outlined its expectations of grantees in the area of consumer involvement. More than any other public or private initiative, the Ryan White CARE Act, through its mandate for consumers' active participation in all facets of program implementation, has contributed to the understanding and appreciation of the enormously valuable resource that people living with HIV/AIDS (PLWH) are to not only Ryan White programs but to all workplaces.

The purpose of this project, conducted by Circle Solutions, Inc. (Circle), was to document the "best practices" of Title IV programs in recruiting, hiring, training, and supervising PLWH as staff members. Information was collected through an extensive literature review, file review of grantees' applications for Title IV funding, telephone discussions with program directors and consumers, and site visits to five Title IV programs.

## **Selecting Case Study Sites**

Following telephone discussions with 30 Title IV program directors, and in collaboration with HAB staff, Circle identified five sites for more intensive study. Selection of case study sites was based on as many of the following factors as possible:

- The site has developed innovative outreach strategies to recruit consumers to the program.
- Consumers have opportunities beyond the "traditional" use of consumers as peer counselors, outreach workers, or volunteers in the program.
- The site has successfully retained consumer employees or significantly reduced attrition.
- Training and education opportunities for consumers and other employees are wide-ranging.
- The site has creatively constructed workplace benefits such as personal leave or sick time, work schedules and flextime, job sharing, and health and other benefits.
- The site has integrated the opportunity for reasonable accommodation into its operations.
- The site has elements of a comprehensive workplace HIV/AIDS policy and program, including specific confidentiality policies.
- The site has taken significant steps to institutionalize consumer employment.



To ensure diversity, site selection was also based on:

- Regional representation
- Urban and rural representation
- Racial and ethnic population representation
- Organizational representation (university-based medical centers, community health centers, state and county public health departments, private medical centers and hospitals)
- Client population representation (women and children, adolescents and youths).

Five programs were identified as meeting many of the selection factors and approved by the HAB Project Officer. These sites were:

- Children's Diagnostic and Treatment Center, Fort Lauderdale, Florida
- The Core Center/Hektoen Institute, Chicago, Illinois
- Justice Resource Institute, Boston, Massachusetts
- Metrolina AIDS Project, Charlotte, North Carolina
- University of California at San Diego, San Diego, California.

## **Conducting the Site Visit**

Circle's project team conducted 2-day visits to these five programs. During the visits, the project team conducted interviews with key informants, including consumer employees; observed consumers in their respective roles and responsibilities at the program; and when possible, observed a training session or sessions of consumers as well as other program employees.

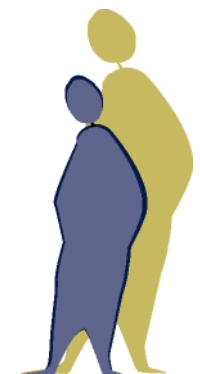
Circle developed a site visit protocol that delineated specific activities to occur prior to the visit, during the visit, and after the site visit is completed.

Activities to occur prior to the site visit included:

- Review of archival information about the site, including Title IV progress reports and materials gathered pursuant to the telephone discussions, in particular consumer outreach/recruitment materials, employee training/educational materials, workplace benefits, reasonable accommodation procedures, and confidentiality policies
- Identification of all key informants, including consumers to be interviewed during the site visit and scheduling of interviews and focus groups<sup>1</sup>
- Identification of any employee training and educational sessions that may be observed

---

<sup>1</sup>Circle's project team worked with program directors and principal investigators to identify consumer employees who would be willing to talk about their experience as employees in the program and to share their recommendations for engaging consumers in all facets of the program. Circle has established policies and practices to obtain consent of interviewees and maintain the confidentiality of consumers throughout the research process and in all written reports.





- Development of on-site interview guides to capture information from the key informant interviews.

On-site activities included meetings with the Title IV program director, the organization director, and the supervisor of consumer employees.

Meeting discussions focused on the following issues:

- The program's history of engaging consumer employees
- Challenges in the recruitment, hiring, and management of consumer employees
- Special needs of consumer employees
- Strategies to overcome challenges and fully engage consumer employees in all aspects of program operations
- Training and educational initiatives for consumers and other program staff members
- Development of reasonable accommodation and confidentiality policies and their implementation
- Steps taken to institutionalize consumer employment
- Recommendations for other Title IV and Ryan White programs.

Focus groups with consumer staff members focused on the following issues:

- Consumers' experience with the program's outreach, recruitment, hiring, and management activities
- Most and least satisfying aspects of their involvement in the program
- Challenges consumers have faced as employees of the program
- Steps that co-workers and supervisors have taken to enhance consumer involvement and productivity
- Recommendations for improvement and enhancement of workplace policies and procedures to support the needs of PLWH
- Other issues as raised by the consumers.
- The on-site protocol and on-site discussion guides for program coordinators and staff are provided in Appendixes A–C.

## Case Studies

After each site visit was completed, a detailed case study was prepared and submitted to both the program's director and the HAB Project Officer for review and comment. The case studies have been compiled in this report titled, *Organizations That CARE: Case Studies of Excellence*.





# *Children's Diagnostic and Treatment Center Comprehensive Family AIDS Program*

**Ft. Lauderdale, Florida**

## **Program Snapshot**

The Children's Diagnostic and Treatment Center (CDTC) is a 501c(3) nonprofit organization that operates under the auspices of the North Broward Hospital District. In 2002, CDTC served more than 9,000 children and families, making it one of the largest providers of children's services in Broward County, Florida. By combining private and public funding, CDTC offers an early intervention program, primary and specialty care clinics, comprehensive family AIDS services, and four different home-based services. CDTC celebrated its 20th anniversary in 2003.

CDTC's Comprehensive Family AIDS Program (CFAP) provides centralized HIV care to more than 3,000 infants, children, youths, women, and families. Most of CFAP's clients are Black or African-American. Comprehensive services offered by CFAP include:

- Social work services
- Medical services (pediatric immunology clinic, adult care clinic, primary care clinic)
- Dental services (through the county health department)
- Research program (AIDS clinical trial group and adolescent trial network)
- Mental health/substance abuse services
- Prevention/outreach program
- Consumer/advocacy program
- Family resource assistance program.

Program staff members are African-American, Haitian, Jamaican, Caucasian, Hispanic/Latino, and biracial. They speak a variety of languages (Creole, French, Spanish, and Italian) and include men and women, a diversity of ages (19 to 56 years), and different sexual orientations. Thirteen of CFAP's 43 staff members are consumers of HIV services.

### **A Place Where You Feel Comfortable**

The lobbies of CDTC and CFAP are adorned with beautiful paintings and piecemeal tile artwork. The artwork is related to children and families of all racial and ethnic backgrounds. CFAP's living center consists of a living room, toys, childcare facilities, vending machines, a well-equipped kitchen, a telephone, a television, and laundry facilities. A friendly face greets you. She understands what you are going through. She is working hard at a job to make ends meet. She is a daughter, a sister, and a mother. She is also a client. This looks like a place where you might be able to spend some time. This is a place where you feel comfortable. This is a place where you will return.



## Organizational Readiness: From Policy to Practice

As early as the mid-1980s, CDTC recognized the importance of “clients helping clients.” Today, as a result of the commitment of CDTC’s director and upper management, consumers are employed at all levels throughout its programs.

At CFAP, consumers have been a part of the staff since 1993, when the first two consumer staff members joined the program as family resource assistants under a grant from Broward County. Over the years, CFAP has continued to expand the numbers of consumer staff members.

CFAP currently employs 13 consumers in four programs:

- **Prevention and Outreach Program.** With two peer educators, this program is based on the peer prevention education model program. Peer educators conduct outreach to HIV-infected and HIV-affected women and make presentations in all Broward County public schools. They also make client referrals to community-based counseling and testing services.
- **Consumer Advocacy Program.** Six consumer advocates provide advocacy services and support to CFAP clients. Services range from welcoming and working with new clients to providing input on new programming and service delivery—linking and supporting clients to medical services, and individual support to clients. Consumer advocates provide supervision of children during appointments and arrange recreational activities for families.
- **Family Resource Assistance Program.** Two family support workers provide referrals to community-based resources for families to ensure that food, medical, and shelter needs are met.
- **Planning Our World Through Education and Research (POWER).** Three youth advocates are part of this new program that provides a drop-in center located in a youth friendly house across the street from CFAP.

CFAP consumer staff members are also involved part-time in other departments throughout CDTC, such as the front desk/reception, the medical records department, the research department, and the primary care clinic. In addition to these consumers who are employed through CFAP, several former CFAP consumers are employed throughout the CDTC organization.

### Notable Achievement

CFAP is the only agency in Broward County that is allowed to send peer educators into the county public schools. In fact, CFAP has presented in every public school in Broward County.

### Voices of Experience

“Consumer staff is the key to getting into the community.”

— Consumer Staff Member, CFAP

“Without consumers, we couldn’t do this work, truly.”

— Director, CDTC



## Policies and Practices to Support Program Philosophy

With the firm belief in the benefits of employing consumers, CFAP has formal and informal policies to support consumer employment:

- Flexible schedules, including full- and part-time options, and flextime that allows for appointments to be arranged in conjunction with work schedules.
- Flexibility of hiring mechanisms that can allow for informed decision making on whether a consumer should or could be hired as an employee or a contractor.
- Flexibility in matching skills to roles and allowing consumer staff members to have a voice in the types of activities in which they would like to be involved.
- A clear message that the program “respects consumers as equal members of the team” and that consumers’ work “must reflect real involvement not tokenism.”
- A regular consumer staff support group facilitated on site.
- An understanding and compassionate place to work where the concept of “mental health days” is understood.
- A formal opportunity for consumer staff members to provide feedback through an employee satisfaction survey.

## Recruiting Consumers

CFAP initially recruited consumer staff members through internal social worker referrals. This process produced mixed results, partially due to biases of the social workers. CFAP now casts a wider net and recruits internally as well as from other HIV/AIDS clinics and programs.

The CFAP program manager cautions to take care when assessing potential consumers’ readiness to work in HIV service programs. Thus, for example, one consumer staff member recommended hiring consumer staff members on a part-time basis to give the program and the staff member the opportunity to assess whether the consumer staff member was ready to take on the job responsibilities.

## Hiring Consumer Staff

CFAP has refined its consumer staff hiring practices to include the following recommendations:

- Conduct a face-to-face, professional interview.
- Talk to candidates about their medical adherence philosophy and determine whether they are committed to promoting medical adherence to other clients.

### Learn More About It!

Even though the job applicant may be a client and well known to the program, it is important to treat an interview as a professional face-to-face meeting. Both parties should prepare for the interview, dress appropriately, and discuss why the program and consumer would benefit from the services of the new consumer staff member. To help the interviewer assess the interviewee’s problem-solving skills, as well as assure his or her written and verbal communication skills, the interview should include:

- Verbal situational issues (that is, “How would you handle this?”)
- Problem-solving tasks written with a pencil/pen and paper
- Written documentation exercises
- Demonstration of presentation skills, if necessary to the job
- Demonstration of computer abilities, if applicable to the job
- Other standard interview questions.

Be sure to include current consumer staff members in the interview process. CFAP includes consumer staff members in the interview process not only when hiring other consumers but also when hiring medical staff members and social workers.



- Gather written recommendations from the candidate's social worker or another individual in a similar position.
- Conduct drug tests.
- Conduct a background check.
- Make sure there is a balance of the job fitting the person and the person fitting the job.
- Carefully consider whether consumer staff members need to disclose their status, especially when hiring youths, and discuss disclosure during the interview process.

## Job Descriptions

Formal job descriptions exist for each consumer staff position and have been customized based on the requirements of the funding source. When possible, job descriptions are broadly defined to allow the job responsibilities to be tailored to the skills of the consumer staff member. CFAP's philosophy is to "let people do what they can do well."

## Designing Compensation Packages

CFAP employs consumers both as employees and as consultants. To qualify as an employee of CFAP, the consumer staff member cannot have a criminal history. Pay scales for consumer employees with a high school diploma or a graduate equivalency degree (GED) are competitive within the pay structures of the parent organization, the North Broward Hospital. As employees, consumer staff members receive full benefits.

Consumer staff members who are consultants do not receive benefits and are paid an hourly rate, which is competitive with employee salaries. The option to serve as consultant allows the program to hire consumers who may not meet the necessary qualifications of an employee (for example, not having a high school diploma or GED). Holding a consultant status allows a consumer to have more flexibility in his or her work schedule and still maintain his or her position within the program.

Consumer employees and consultants receive pay increases that are based on performance. Performance reviews occur annually.

## Orientation of Consumer Staff

All staff members, including consumer staff members, are oriented with a multi-day HIV 101 course. New hires shadow employees who hold similar roles and responsibilities. Every effort is made to clearly define roles and expectations. Consumer staff members sign letters of agreement indicating that they have been trained in their new roles and responsibilities. In addition to HIV 101 and specific skill-based training, consumer staff members are oriented to organizational issues, including:

### Advice from the Field

Revise job descriptions as roles and responsibilities evolve and review them annually to make sure they are accurate. A good time to do this might be around the time of the consumer staff member's annual review.

Do not underestimate the amount of time needed to revise job descriptions or to conduct a thorough hiring.

### Voices of Experience

"Consumers should have the opportunity for growth and increased responsibility."

— Manager, CFAP



- CDTC departments and programs
- Timesheets and paychecks
- Professionalism (dress code, attitude and performance, rumor and gossip, drama and personal problems, what to do if coming in late, not lending money out to clients or peers)
- Confidentiality
- The different job roles in CFAP
- Smoking policy
- Completion of documentation (time logs, time sheets, mileage sheets, data collection)
- Reporting work problems
- Work role versus client role (making appointments at appropriate hours)
- Drug and alcohol use
- Termination and voluntarily leaving.

Consumer staff members are expected to understand confidentiality policies and to sign a confidentiality agreement stating that they understand these policies. Thirty days after consumer staff members begin working, they receive a performance review.

## Designing Training for Consumer Staff Members

“Lunch and learn” are monthly in-service training sessions that are mandatory for consumer staff members. Usually organized by the medical staff members, these sessions address a wide range of topics, including:

- General communication skills and telephone etiquette
- Dealing with difficult clients and providers
- Personal relationships with clients
- Handling difficult client/clinician conflict
- Current medical treatment for HIV/AIDS
- Secondary prevention strategies
- Confidentiality and disclosure.

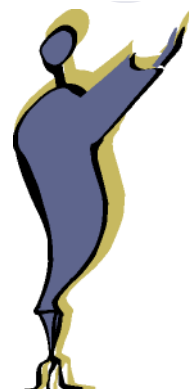
Whenever possible, the lunch-and-learn sessions include role-playing exercises to allow for practical application of new skills. In addition, in lieu of onsite training, consumer staff members visit various community programs to better acquaint themselves with program referrals.

The program director encourages consumers to attend trainings that are offered locally and often free of charge. Many consumer staff members, including two youth advocates, have attended national conferences in Washington, D.C.

### Learn More About It!

CFAP's experience in hiring consumers and designing compensation packages that best fit consumers' needs has resulted in the following recommendations/considerations:

- **Compensation.** Consumer staff members may be allowed to choose their employment status (employee or consultant) depending on (1) qualifications and/or requirements set by the parent organization; (2) existing pay structures within the parent organization; (3) the needs of the individual consumer staff member, especially with respect to their state and federal benefits; and (4) the needs of the program to have a full complement of staff members available to meet the needs of clients.
- **Benefits.** Consumer staff members may be allowed to choose the types of benefits they receive. For example, consumer staff members can choose to participate in either a health maintenance organization (HMO) or preferred provider organization (PPO). When choosing a plan, staff members must consider the required waiting periods and provider participation in their selected plan.





# Supervising and Supporting Consumer Staff Members

## Scheduling to support both consumer staff members and the needs of the program

Providing an array of services, the program is extremely busy on a daily basis and thus greatly depends on its staff, especially consumer staff members. Even in a flexible work environment, planning and scheduling is key to ensure that the social workers have the consumer staff support they depend on each day. CFAP has developed a supervision and support structure that allows consumer staff members to gain a variety of skills, work in areas that best suit their strengths, and simultaneously give the program adequate staffing coverage to continually provide services to the many clients served daily by the program. Supervisors work with each consumer staff member to set the schedules, and then a schedule is posted in a common area.

## Preparing consumer staff members for other workplaces

CFAP understands that it has a unique opportunity to provide consumer staff members with a range of work experiences that will be beneficial to them should they decide to seek employment outside of CFAP. As such, supervisors often assign consumer staff members to a variety of job functions based on the needs of the program at particular times. This strategy benefits consumer staff members by building their skill sets, adding variety to their workload, and allowing consumers to identify their professional strengths. The strategy benefits CFAP because it allows the program to consistently meet the needs of their clients even on days when staff members take sick leave or are on vacation.

## Support and supervision

Adult consumer staff members meet monthly with their supervisor, who is not their mental health provider or social worker. During these meetings, the consumer staff member and supervisor review workload and address the challenges that arise. In addition to work-related supervision, consumer staff members participate in individual counseling sessions and consumer staff support groups led by a social worker. Group counseling and support has been a long-standing support mechanism for consumer staff members at CFAP.

CFAP administrators acknowledge that supervisors must be able to address a broad range of emotions and potential conflicts when working with consumer staff members. For example, a particularly delicate situation is the termination of a consumer staff member who still needs to receive services from the program. In such cases, CFAP supervisors work very carefully to ensure that the terminated consumer staff member feels comfortable continuing to receive services from the program. Administrators contact the former staff member a few days later to let

### Learn More About It!

CFAP has a cork bulletin board in a convenient location within its office where important information such as schedules, contact information, job stations, and responsibilities is posted. To aid in keeping track of staff schedules, it may be helpful to keep and post a weekly "master schedule" of all staff members, their contact numbers, and their hours.





him or her know that CFAP is still supportive and that services are always available, regardless of person's employment status.

### **Supervision of youth consumer staff members**

Youth consumer staff members are supervised by two social workers. Although they work together daily, supervisors formally meet once a week with youth staff members to discuss progress in outreach and education efforts. In addition, the youth program director is very involved in providing supervision.

Supervision of youth advocates is an additional challenge. CFAP has learned that youth consumers need firm guidance, encouragement, and support, with clear expectations. Furthermore, CFAP believes that youth consumers need special assistance in goal setting as well in identifying appropriate behavior during and outside of work. Finally, because youths are very energetic, they often respond well to being kept busy and engaged at all times.

## **Creating an Organizational Climate of Support**

CFAP is committed to continued support of its consumer staff members. CFAP recently assessed the needs of consumer staff members by administering a satisfaction survey. This survey created an opportunity for each consumer to provide individual feedback and suggestions. The survey has helped improve services to clients, improve job satisfaction, and ensure that consumers are assigned to tasks that best use their talents and abilities. Finally, the survey helps to not only identify workplace problems but also to offer solutions to any problems. Project directors (or survey administrators) have been very clear and reassuring that all constructive ideas and criticism will be accepted.

### **Voices of Experience**

"This job has completely changed my life. It is the best thing. I look forward to coming to work everyday."

—Consumer Advocate, CFAP

"It is hard to get close to clients. It is hard when clients die. But the program helps to support us through it, and we can support the clients."

— Consumer Advocate, CFAP

### **Learn More About It!**

**Satisfaction Survey.** The following questions provide an example of a consumer staff member satisfaction survey:

- Do you like your job?
- Do you feel your job is important? Why?
- Are there more things or different things you feel you are able to do? What?
- Do you feel that there are things you would like to do that you are not able to do right now?
- Describe how you would like to change/improve your job.
- Additional comments:



## Highlights of Program Policies and Other Materials

Policies and Other Materials	Specific Program Examples
Job descriptions	Community Consumer Advocate Family Support Worker Research Assistant Peer Educator Community Outreach Worker
Written compensation/benefits	Description of consumer consultant benefits
Policy on consumer involvement	Client advocate/vendor agreement
Written expectations of consumer/employee agreement	Consumer consultant agreement
Orientation/training materials	Vendor training agenda Client engagement training
Use of satisfaction/feedback surveys	Consumer advocate survey

### Program Contact

For further information about the Comprehensive Family AIDS Program, contact:

Marie Brown Hayes

Program Manager

954-728-1082

[mbrown@nbhd.org](mailto:mbrown@nbhd.org)



# *The Core Center/Hektoen Institute Women and Children's HIV Program and the Adolescent HIV Program*

Chicago, Illinois

## **Program Snapshot**

As one of the largest HIV/AIDS service providers in the Midwest, the Core Center (Core) provides comprehensive HIV/AIDS services for both adult and youth clients. Core manages five clinics devoted to women and children and is affiliated with the Division of Adolescent Medicine, Stroger Hospital of Cook County, and the Hektoen Institute, which serves as Core's administrative and fiduciary agent. The women and children's program, as well as the adolescent program, provides outreach, case finding, counseling, medical and mental health treatment, and educational services. Conveniently located in the "medical corridor" of Chicago and easily accessible by public transportation—a real advantage for both clients/patients and program staff members—Core serves as a "one-stop shopping" resource for HIV-affected families and youths. In addition, a Pediatric AIDS Research Program conducts short and long-term medical and mental health research studies and employs consumer staff members as research assistants, community health advocates, research case finders, and outreach research staff.

Both the women and children's program as well as the adolescent program provide services under a multi-disciplinary medical team model that includes physicians, nurses, and mental health and social services professionals who work collaboratively with consumer staff members to provide comprehensive client/patient services. Both programs employ consumer staff members in full- and part-time positions. As a part of the Cook County Hospital System, consumer staff employees are members of the labor union that represents hospital personnel in the county.

## **Organizational Readiness: From Policy to Practice**

When asked how Core came to engaging consumer staff members, the Program Coordinator of the Women and Children's Program quickly acknowledges, "once we got the buy-in of the Medical Director that consumers would significantly enhance our outreach, education, and

### **Learn More About It!**

The multi-disciplinary medical team model allows case management teams, which are composed of a broad range of professionals and peers, to develop and implement complex, comprehensive medical, mental health, prevention, and social services for women and children and families. The engagement of consumer staff members as members of the case management team allows them to be a critical part of a patient's/client's treatment. However, the model is difficult to implement and requires the acceptance of consumer staff members as key participants in service delivery.



clinical services, he immediately sent the message throughout the organization—“this is the way we are operating!” Similarly, the Adolescent Program Coordinator echoed the organization’s strong commitment to engaging youth consumer staff members in service delivery. “While we know that it is challenging and many times difficult working with youths as staff members, we recognize that this program could not be as effective unless we engaged youths at all levels,” notes the Adolescent Program Coordinator.

Although Core’s personnel policies mirror those of Cook County, the organization’s philosophy of honoring and maximizing the skills of consumer staff members is evident. Specifically, Core:

- Sets high standards and expectations for consumer staff members and operationalizes these expectations with a code of conduct and agreement.
- Holds managers accountable for mentoring, supervising, and encourage consumer staff members to continually improve their knowledge and skills.
- Expects that all staff members, including consumer staff members, understand and abide by the mission to provide excellent services to patients/clients.
- Assessed how consumer staff members could enhance program services and engages consumer staff members in a wide range of positions throughout its programs.
- Uses performance evaluation to “put teeth” into the program’s commitment to provide stellar service.

Both adult and youth consumer staff members are, in the words of the Adolescent Program Coordinator, “legitimate members of our interdisciplinary teams.” Thus, consumer staff members play key roles in every aspect of outreach, education, and service delivery for the programs. Recognizing that consumer staff members often require intensive supervision and guidance, Core has strategically developed organizational policies and procedure to ensure that youths:

- Understand that the program’s needs and values their involvement.
- Are provided continuous support and supervision from both a clinical case manager (who provides mental health counseling) as well as an administrative supervisor (who addresses job-related issues).
- Understand role boundaries and, in particular, understand the importance of maintaining professional relationships with both adult staff members as well as youth clients who are served by the program.
- Are provided with clear guidance about the program’s expectations of them as well as the program’s commitment to ensure their success as consumer staff members.



## Policies to Support Organizational Philosophy

An overarching theme in all of Core's organizational policies is an unwavering commitment to organizational ethics. Thus, policies and procedures support the ability of both the adult and youth programs to address potential conflicts of interest and to couch personnel decisions with a framework of "what is the right and ethical approach to this?" As a consequence, the program has addressed a number of difficult issues, including the personal relationships between youth staff members and adult staff members and personal relationships between youth staff members and the youth clients they serve.

Core's commitment to ethical organizational policies and practices is reflected in the program's:

- Formal workplace policy on life-threatening diseases and disabilities
- Policy on consumer involvement
- Philosophy of separating clinical and administrative supervision
- Policy on the professional relationships between staff members and clients
- Philosophy of creating an organizational structure that supports youths (both staff members and clients) physically and emotionally
- Policies on confidentiality
- Flexible approach to reasonable accommodations for all staff members, including those living with HIV/AIDS, which includes:
  - Documentation of time
  - Flextime when illness or medical appointments require absence from the workplace
  - A process to allow for exceptions for extenuating circumstances
  - A formal communication process to ensure that no one is perceived as receiving special treatment.

## Recruiting Consumer Staff Members

Core recruits consumer staff members primarily from its client base, although the organization has established a superb network of community partners and planning councils that provides a wide network for recruiting consumer staff members. Both the adolescent and the women and children's program coordinators described the advantages of recruiting from the client base:

### Voices of Experience

"Some youths expected that their relationship with their case manager would be personal. We worked very hard to develop policies and procedures that clearly help youths understand that we are professionals who are always working to define boundaries, that we provide quality services and a continuum of care for youths, and that we always have their best interest at heart."

— Adolescent Program Coordinator, Core



- Staff members are able to observe potential candidates over a long period of time and can determine when a client is ready to become a staff member.
- Staff members have the opportunity to observe and understand the strengths and weaknesses of potential candidates and are better equipped to address any issues that consumer staff members may have as they make the transition from client to colleague.
- Consumer staff members have the time and opportunity to learn how Core programs operate and can become very familiar with the organizational culture. Thus, they can more easily become a part of the organization than a consumer staff member hired from outside the organization.
- Consumer staff members can observe the positions and opportunities that are available within the Core programs and can assess, for themselves, which positions are best suited for their interests, skills, and availability.

For example, within the youth program, the transition from client to staff member occurs when youths are recruited to serve as “buddies”/peer educators. These consumer staff members are paid a stipend, and they provide valuable education and support to youth clients. In turn, the program provides on-going education and mentoring to “buddies”/peer educators. Regularly scheduled staff meetings allow youth staff members to share information about their work with their peers, supervisors, and the other team members of the program. Because the philosophy of the program is to integrate and use every staff member as part of an interdisciplinary team, youth staff members have enormous opportunities to learn and grow with the program.

Both the adolescent and the women and children’s program coordinators stressed the importance of gaining full support or “buy-in” from the Core professional staff members before employing consumer staff members. This is particularly important at Core because the organization operates and is committed to an interdisciplinary model of services delivery, which engages physicians, nurses, psychologists, social workers, and consumer staff members in service delivery. As the youth program coordinator noted, “if there is no staff buy-in, you will not only lose the consumer as a staff member, but you risk losing the consumer as a client as well.”

## Hiring Consumer Staff Members

Consumer staff positions are dictated by program needs and not created around the consumer. In fact, one of Core’s many successes in the hiring arena has been the ability to develop and expand job descriptions for consumer staff members as the organization’s needs change. For example, Core’s strong commitment to quality service delivery led to the development and implementation of a client/patient grievance procedure

### Voices of Experience

“Be clear about expectations and understand that recruiting, hiring, and supervising consumer staff as it is a time-consuming and challenging effort—but incredibly rewarding—for both the program and the staff.”

— Women and Children’s Program Coordinator, Core

“When recruiting a youth peer educator, look for someone who is stable, has had a good deal of time to come to terms with their disease, is adherent to their medications, has good listening skills, can be open in their communication style, and has the maturity to adhere to the confidentiality policies.”

— Adolescent Consumer Supervisor, Core

### Voices of Experience

“I first came to Core as a volunteer and then was hired as a peer educator. I was then promoted to case finder. The staff members here push you to learn more everyday; they care about you personally and professionally.”

— Youth Consumer Staff Member, Core

“I feel that the sky is the limit here at Core. The program opens opportunities for you if you are willing to work hard and learn. I love it here and will stay for a long time.”

— Consumer Staff Member, Core





that is directed by a 10-year consumer employee whose role as a client/patient advocate evolved over time.

Core's hiring process for consumer staff members mirrors that of any other staff member and includes the following elements:

- Formal job descriptions are developed for all staff positions.
- Consumers must submit resumes and participate in a series of formal interviews. Although it may be an intimidating process, consumer candidates are required to treat their interviews with professionalism.
- Consumers are encouraged to pursue promotion into other areas based on their experience and interest.
- Managers are encouraged to "think outside the box" and value the life experience of candidates.

## Designing Compensation and Benefits Packages

Because the salaried consumer staff members are represented by the county labor union, compensation and benefits for staff positions at Core are comparable to those offered for similar positions in the county. Pay structure within the organization applies equally to both consumer and nonconsumer staff members. In addition, the program's philosophy of "how can we maximize consumer involvement throughout the organization?" is supported by the flexibility to look at each employee's unique situation. Thus:

- Some positions, such as the "buddies"/peer educators, are paid on a stipend and work flexible hours.
- Individuals can also negotiate a shorter workweek or can be hired under contract rather than as a part-time employee to retain benefits.

## Orientation and Training of Youth Consumer Staff Members

All new staff members receive orientation that includes:

- Introduction to program staff members in all departments
- Review of program policies and procedures, including confidentiality policies
- Role boundaries and ethical decision-making
- "Shadowing" of other staff members who perform similar roles
- Initiation of regular individual clinical support with a Core staff member not working directly with the youth employee.

Specialized training includes sessions addressing:

- HIV 101

### Learn More About It: Client Advocacy Procedure

This procedure provides a formal mechanism to address client complaints. Clients can file a complaint by completing a short form. The complaint is followed-up by a patient advocate and reviewed by the patient advocate director. The director works with Core employees, including medical and mental health providers as well as the management structure of Core, to resolve the complaint. Clients are advised of the "next steps." When necessary, changes are made in organizational policies and/or additional training is provided to employees to ensure that the organization continues to provide excellent client services. For more information, contact Gigi Nicks, Director of Patient Advocacy, at 312-572-4738 or [gnicks@corecenter.org](mailto:gnicks@corecenter.org).

### Voices of Experience

"I feel that we are paid fairly. I have checked with other agencies, and I think Core does a much better job of being fair not only with pay but with the opportunities to expand and grow with this job. It would be hard to leave here for something better."

— Consumer Staff Member,  
Core



- Sexually transmitted disease
- Public health system in Cook County and accessing resources
- Adherence to medication
- Outreach and counseling skills.

In addition to in-house training, both youth and adult consumer staff members are encouraged to attend local training programs addressing HIV, substance abuse, and mental health issues as well as attending training programs to enhance administrative and office skills. Despite resource limitations, Core remains committed to doing everything possible to continually enhance the knowledge and skills of youth consumer staff members. The organization's philosophy of investing in youth staff members is apparent. As the program coordinator noted, "we set high expectations for our youth staff members, and we try to the best of our ability to train and educate them in a way that they have the skills to live up to those expectations."

## Supervising and Supporting Consumer Staff Members

All consumer staff members have averaged 3 or more years of employment with Core. Some youth consumer staff members started with the program as youth volunteers and have transitioned to adult staff members. The longevity of these youth and adult consumer staff members is a testament to the quality of the supervision and support that the program provides. With a very strong commitment to the value of youth and adult consumer staff members and an organizational philosophy steeped in "taking the ethical high road at all times," the program has designed a supervisory process that facilitates the success of both the youth staff members and the program as a whole.

The Adolescent and the Women and Children's Program Coordinators are quick to acknowledge that supervision is not a 9-to-5 job but rather a time-intensive commitment. In particular, the Adolescent Program Coordinator clearly draws the appropriate boundaries with youth consumer staff members. She notes that supervising youths requires an understanding that youths can be:

- Cognitively and developmentally challenged
- Unpredictable
- Inexperienced in a professional work environment
- In need of extensive mentoring.

However, she unabashedly admits that the program operates with a philosophy that:

- Youths must be a legitimate part of the interdisciplinary team that serves the program's clients.
- Youths must have high expectations set for them and must be held accountable.

### Voices of Experience

"They [the staff] are always encouraging you to learn more and more. One of the doctors—and others—I work with is always encouraging me to go back to school. He just believes in me."

— Youth Consumer Staff Member, Core





- The program needs to articulate by word and actions that the program needs the youth consumer staff members in order to deliver quality service—professional medical, mental health, and social services are not enough for quality comprehensive services.
- Supervisors need to continually remind and demonstrate to youth consumer staff members what their work does to improve service delivery.
- The program will never tolerate any staff member stepping over appropriate professional boundaries.
- Confidentiality is crucial in all situations.
- Supervisors must have the time and the desire to mentor youth staff members.
- Clinical supervision and administrative supervision must be done by separate individuals, which is beneficial for both the supervisor and the youth staff members and contributes extensively to clarifying roles and boundaries.

In addition to this extensive programmatic support, youth staff members participate in biweekly individual meetings with their supervisor and in weekly group meetings. Monthly meetings, with the entire interdisciplinary team, help supervisors to mentor youth staff members. Supervisors carefully document attendance at work and job performance; they also conduct annual performance evaluations. Newly hired youth staff members are placed on a 3-month probationary period and are given feedback on their performance within the first month of their employment. All of these performance evaluation points are designed to identify the strengths and weakness of the staff member early in their career at Core, to design strategies to address areas for improvement, and to build the job skills of youth staff members.

Supervisors hold monthly meetings to share information about issues and strategies related to their supervisory roles. While acknowledging that many of the program's supervisors have not participated in formal management/leadership training, the Adolescent Program Coordinator noted that the interdisciplinary team model of service delivery has allowed supervisors access to a wide range of highly trained and skilled professionals who bring their supervision experience to the program.

## Creating an Organizational Climate of Support

The organizational climate created by Core exemplifies a workplace that has strategically assessed how and in what roles of both youth and adult consumer staff members can contribute to the program's goals; designed staff positions that allow the program to provide the best possible services to their clients; created strong supervision and support for consumer staff members; invested in extensive, skill-enhancing training; and created a staffing structure to allow consumer staff members to grow professionally and be promoted within the organization. Finally, the

### Voices of Experience

"The staff members are my role models. I want to be a pediatrician."

— Youth Consumer Staff Member, Core



organization demonstrates a continual emphasis on sustaining and enhancing an ethical workplace, where boundaries are clear and respect for individuals is paramount.

## Highlights of Program Policies and Other Materials

Policies and Other Materials	Specific Program Examples
Job descriptions	Job descriptions for all youth consumer staff members, including: Case Finder Research Assistant/Associate Peer Educator Research Case Finder Consumer Supervisor
Written compensation/benefits	Description of consumer consultant benefits
Policy on consumer involvement	Client advocate/vendor agreement
Written expectations of consumer/employee agreement	Consumer consultant agreement Youth peer educator contract and agreement Adult contract and agreement
Orientation/training materials	Program orientation materials and checklist
Confidentiality policy	Written confidentiality policy

### Program Contact

For further information about  
Core's Adolescent HIV Program, contact:  
Felicia Rodriguez, Program Coordinator  
312-572-4955 or 312-282-3343 (cell)  
[frodrig312@aol.com](mailto:frodrig312@aol.com)

For further information about  
Core's Women and Children's HIV Program, contact:  
Deane Taylor, Program Coordinator  
312-572-4845  
[dtaylor@corecenter.org](mailto:dtaylor@corecenter.org)



# *Justice Resource Institute*

## *JRI Health*

**Boston, Massachusetts**

### **Program Snapshot**

The Justice Resource Institute (JRI) was founded in 1973 and is one of the largest human services providers in the Commonwealth of Massachusetts. JRI manages a health center and mental health clinic; a street youth outreach program; court and probation consultative services; residential schools for mentally ill, cognitively limited, developmentally disabled, and behaviorally challenged youths; and comprehensive services for adults who are developmentally disabled.

JRI Health, a division of JRI that is accredited by the Council on Accreditation,<sup>2</sup> provides underserved individuals and communities with opportunities to develop the tools and skills that are essential for creating strength, well being, and autonomy. JRI Health offers an array of programs that, in combination, provide a comprehensive circle of health, mental health, substance abuse, and housing services, as well as outreach to street youths.

The primary populations served are persons living with or at risk for HIV/AIDS; gay, lesbian, bisexual, and transgender adolescents and adults; troubled adolescents; and persons with a broad range of disabling conditions. JRI Health supports agencies serving similar populations through its community-advocacy and capacity-building programs.

Additional services are offered under a subcontract to Boston's Fenway Community Health Center (expedited mental health services for JRI Health clients), the Emergency Department of Boston Medical Center (HIV counseling and testing), and Boston Area Gay and Lesbian Youth (BAGLY; case finding and HIV counseling and testing).

### **Organizational Readiness: From Policy to Practice**

Although JRI Health has a strong commitment to employing and retaining consumers in staff positions, it does not have any formal workplace HIV policy. Informally, the organization takes a flexible approach to consumer employees by offering "reasonable accommodations" to permit employees to address health issues and

---

<sup>2</sup>The Council on Accreditation is an international, independent, not-for-profit, child and family services and behavioral health care accrediting organization.

#### **Voices of Experience**

"We are willing to sacrifice program efficiency to support people. Staff [members] feel taken care of if they feel they have access to the resources of the organization."

— Vice President,  
JRI Health

#### **Voices of Experience**

To facilitate consumer recruitment, according to the JRI Health's program director, "Utilize your client base. Let it snow ball; let them take the lead: they are the experts. Go to them first; allow them to spread the word. [Also,] include [consumer staff] in developing job descriptions."



fulfill job responsibilities. JRI Health's example suggests that organizations lacking formal policies can, nevertheless, offer similar supports.

### Setting high expectations

Central to JRI Health's philosophy and practice is the concept of *modeling behavior*. Consumer staff members, in higher level positions, encourage those they supervise to meet, if not exceed, expectations by modeling professional behavior. Although the program clearly recognizes that youths as employees may present special challenges and often need very consistent and focused supervision, JRI Health's policy and practice is to expect excellence and professionalism from their youth consumer staff members and thus encourage supervisors, through their own example, to create work environments that mirror adult workplaces.

Although JRI Health's program director admits that it is sometimes difficult to set limits for youths, some rules are strictly enforced. For example, youth employees who do not maintain contact with the program during an extended absence are dismissed. Administrators encourage employees with attendance difficulties to bring these issues to their clinical supervisor, who is a licensed mental health counselor not affiliated with the program.

### Recognizing the need for flexibility

Understanding that youths may experience deteriorating health during the time of their employment, JRI Health's policy, as well as its practice, is to do everything possible to accommodate youths in the workplace as well as with their treatment needs. The program offers a number of options that allow youths to continue working, either moving from full-time employment to part-time employment or by working from home, as they deal with their periods of illness.

## Recruiting Youths

With a strong commitment from top management to recruit and mentor a diverse staff from within the organization, internal recruitment has been central to JRI Health's workplace approach. In particular, peer support groups have served as a fertile resource for identifying potential candidates for employment. During these group interactions, JRI Health staff members can observe the skill sets and personal qualities exhibited by youths who may become a good employee.

One innovative approach to recruitment is a monthly HIV+ Direct Client Services Networking Breakfast, where job announcements are distributed. These breakfast meetings provide continuing education on a variety of issues of interest to participants. The location of the meetings rotates to accommodate the participation of a broad range of service providers.

Along with word-of-mouth and job announcements within the organization, JRI Health advertises positions in the local gay press, noting that "experience" or "familiarity" with HIV is desired within the

### Learn More About It!

The following guidelines may be used to recruit for a peer position.

- **Circulate position opening where HIV-positive peers will see it.** Use resources that HIV-positive people access, such as drop-in centers and other HIV-related programs, community magazines and publications, coffee shops, and other settings where HIV-positive people commonly visit.
- **Position description must have appeal.** Age and culturally appropriate marketing is key. People typically respond to catchy flyers and posters more commonly than to dense, small-type agency position descriptions. Convert the original position description into a flyer, with large bold print. Highlight the relevant information and include hourly wage, position title, key responsibilities, and job requirements.
- **Word of mouth is a sure bet.** Telephone people within your network of providers and urge them to inform staff and clients about the available staff position. Provide a brief announcement at other agencies' staff meetings or youth groups to spread the word about a position opening.



candidate pool, thus letting consumers know that they are welcome to apply. Youths feeling “wanted” by the organization, together with a willingness to modify or match jobs to people’s interests, assures that consumer staff members are engaged in the workforce.

## Hiring Consumer Staff Members

JRI Health has a highly detailed and well-documented approach to job creation that includes job descriptions (created by the program director with input from staff members), candidate outreach, resume review, interviewing strategies, and hiring processes. Questions a program may wish to consider asking when evaluating a prospective job candidate include:

- What skills will the individual need to best carry out the given responsibilities of the job?
- What kind and how much relevant work and/or field experience will the individual need in order to succeed?
- What special skills and/or unique perspectives and experiences should the final candidate possess?
- Who will be the individual working with both inside and outside of the agency (staff versus clients)?
- What type of a work schedule will be required of the individual?

JRI Health sometimes finds it useful to rank individuals using a scoring method that assigns scores (0–3) to different sets of criteria. Candidates who score high (for example, all 3’s) on all of the criteria will be considered for an interview, whereas candidates who score low (for example, all 0’s) most likely will not be considered. Areas that may be rated are work and/or life experience, education and training, related skills, and cultural competency. It is important to note that scores should only be used as guidelines and do not necessarily reflect a final decision.

Finally, the hiring process includes a criminal background check for new employees. Because this background check may take as long as a month to complete, all hiring is contingent upon the criminal background check report, and this should be outlined clearly in the employment offer.

## Hiring in the Spirit of “Offering Opportunity”

JRI Health views hiring as a way to not only meet the staffing needs of the program but also as a means of offering much needed work experience to youths. Thus, the organization sees consumer staff positions as skills-building positions and does not necessarily expect longevity among consumer staff members. In fact, the average tenure for nonadministrative positions in the HIV+ Support Services Program is about 1 year. Supervisors are encouraged to support consumer staff members to seek higher level and higher compensated employment,

### Voices of Experience

“Choose people with open personalities ... people that show drive and have a reputation as a hard worker.” Another staff member noted that recruiting from a program’s internal network of youths “gets a rapid response” and that “prior membership [in an organization] plus personal relationships make it easier to do the work.”

— Consumer Staff Members, JRI Health

“Peer support is a key factor. If you are trying to reach youths, you need youths.”

— Youth Consumer Staff Member, JRI Health

### Notable Mention

The program hired its first minor employee last year: a 15-year-old young woman who served as a mentor to participants in the Children’s AIDS Program during the school year. The program director arranged for her working papers, and she was provided with close clinical supervision. The program director urges others who plan to employ minors to learn more about procedures for obtaining working papers to ease the entry of such employees into the workplace.



either outside the program or within the program itself. For example, the current program director began his involvement with JRI Health in a “peer” position, ascending to his current role through a series of internal promotions. Such an approach, although potentially challenging to program stability, appears to have worked well for JRI Health.

## Designing Compensation Packages

Compensation for full- and part-time staff positions at JRI Health is comparable to compensation offered for similar positions in other local agencies. Pay structure within the organization does not vary by consumer status.

Employees working 20 hours or more are eligible for benefits. Health insurance is offered with a 25 percent to 30 percent employee co-pay; long-term disability, dental benefits, and life insurance are fully covered. In addition to 12 paid holidays and 3 personal days, there are generous vacation benefits: 2 weeks in first year of employment, 3 weeks in the second year, and 4 weeks in the third and subsequent years. JRI Health’s vice president notes that cost-of-living raises are provided each year, even when programs are flat-funded. Consumer employees who do not qualify for health benefits are able to participate in Ryan White–funded entitlements.

## Orientation of Consumer Staff Members

JRI Health developed a *Guide to Staff Orientation* for all new employees. This guide provides a tabular schedule of topics and timelines that responsible staff members sign-off on and date as topics are covered. When new employees begin their jobs, JRI Health attempts to complete all necessary paperwork as quickly as possible and to schedule all essential orientation sessions as soon as possible after hiring. A meeting with JRI Health’s business manager occurs within the first week of employment and includes the presentation of the confidentiality policy, the signing of a confidentiality statement, and discussion of the rules of conduct, including sexual harassment policies.

Underlying the concrete tasks of orientation is an effort to convey JRI Health’s cultural values regarding social justice to new employees. A new staff member reflects the organizational culture in stating, “I don’t think of [a colleague] as a person with HIV; they’re just another person to me.”

The program director encourages other program managers to ensure that new hires “really shadow staff” throughout the orientation process, which might actually take several months. The program director urges that program managers “really invest in [new hires]” and that they “be available.” Staff members echoed these thoughts, noting that much of the learning is hands-on and that supervisors must be ready to respond to questions.

### Voices of Experience

“We’re seeking (a position) that will be helpful in their lives, and we are willing to work with the direct supervisor of employees to rewrite job descriptions to match skills and interests of new hires.”

— Program Director,  
JRI Health

“Focus on potential. Draw ideas and feedback from candidates. ‘This is an opportunity; what ideas do you have? What ways can we do things better?’ They own all this!”

— Program Director,  
JRI Health

### Voices of Experience

“Everyone, from full-time managers to part-time peers, receives the same welcome. Attentiveness to the individual is essential, providing a sense of collaboration [for employees working at all levels.”

— Vice President,  
JRI Health



## Training for Consumer Staff Members

Several training opportunities are required for all new employees. The first is a peer provider training (based on *Peer Support Standards of Care*, developed by the Boston Public Health Commission for Title I agencies in Boston), for which the program has direct funding. Two training sessions are offered by the Massachusetts Department of Public Health: case management training, and HIV and hepatitis C training, the funding of which is built into the program's training budget. In addition, there is a 2- to 3-day JRI support group facilitator training program that is scheduled from spring through fall, with two winter programs scheduled in November and January.

Supervisors continually assess training needs. As a result, training issues that have emerged include ethics and boundaries and refining group facilitation skills. The program director, as well as the supervisors, regularly asks consumer staff members to assess the training to ensure that employees' needs are met and that the training is effective.

### Voices of Experience

"It is important to learn to slow down and prioritize. Programs must train a lot, but expect a lot as well."

— Consumer Staff Member,  
JRI Health

## Creating an Organizational Climate of Support

Consumer staff members receive administrative support from the support group coordinator, the program director of HIV support services, and the vice president of JRI Health programs, who also facilitates the JRI Health CAB meetings.

All current staff members have, at one time or another, sat on the CAB. JRI Health's vice president believes that this direct feedback loop to the senior administrator at JRI Health helps consumers to feel heard "from the top." In fact, program changes have resulted from CAB input, demonstrating to consumers that their "opinion counts" and that administrators at the highest levels of the organization care about the issues that are important to them. This mechanism is perceived as one that promotes more buy-in, attendance, and participation in CAB meetings as well as retention of consumers at all levels of the organization.

### Supporting employees' needs

Candidates living with HIV are attracted to staff positions by JRI Health's commitment to "make sure staff [members] are plugged into services they need," according to the program director. The organization's philosophy and practice are to allow consumer employees to continue to receive services through JRI Health, if that is their choice. In this way, consumers are empowered to "take ownership" of their own health care. Consumer staff members participate in group, as well as individual, clinical supervision as needed. Employees are referred for psychotherapy when such services are requested and needed.

Although employees generally work under 3- to 6-month contracts, thus allowing for advancement to other work opportunities or for youths to “age out” of the program, the average length of employment for a consumer staff member is about 1 year. With career advancement on the agenda from the start, supervisors focus on career goals and present options for further training or returning to school. To support employees in their desire to further their formal educations, JRI offers a tuition reimbursement benefit. Although career advancement and/or returning to school requires the program to continually recruit, hire, and train new employees, the long-term benefits for consumer employees far outweighs the challenges associated with a high turnover of employees.

JRI Health’s commitment to creating an organizational climate of support is further enhanced by the practice of conducting exit interviews with all employees. The interviews are conducted in person (that is, “face-to-face”), and a questionnaire can be completed privately by the employee. This feedback is incorporated into organizational planning through JRI Health’s governing body.

### **Applying the mission statement to daily practice**

The organizational aspirations described in JRI Health’s mission statement are applicable to JRI Health’s philosophy regarding employee retention and the ultimate extension of youth employees into the world of adult work. Their example suggests that those programs demonstrating respect for consumer input and valuing feedback from employees at all levels (even in the context of exiting employment) are more likely to retain employees who bring value to the organization to the extent that retention serves all parties concerned.

Because turnover in such a program can be high, JRI Health’s vice president advises fellow senior administrators to be prepared to rationalize decisions that support employees exiting the program to funders and managers. To do this, however, “you have to be convinced that what you’re doing is right.”

### **Learn More About It!**

JRI Health’s Mission Statement. “JRI Health affirms each individual’s right to be treated with dignity and respect; to learn, change, and grow; and to experience a full and productive life. It is our responsibility to assist the individuals and families we serve to maximize their potential as whole persons and as valued members of their communities. Although our range of services is as varied as those we serve, our approach is uniformly characterized by compassionate support, innovation, and community leadership.”





## Highlights of Program Policies and Other Materials

Policies and Other Materials	Specific Program Examples
Job descriptions	Client Advocate Community Health Specialist Mentor POZ 20s Woman Facilitator Support Group Coordinator
Recruitment materials	Recruiting and hiring guide
Written confidentiality policy	Written confidentiality policies
Hiring guidelines	Recruiting and hiring guide
Written expectations of consumer/employee agreement	Written expectations of consumer
Orientation/training materials	JRI Guide to Staff Orientation JRI Support Group Facilitator Training: Trainer's Manual
Exit interviews/policies	JRI exit interview and policy

### Program Contact

For further information about  
JRI Health's programs, contact:

Troix Bettencourt

Program Director

617-988-2600, extension 205

[tbettencourt@jri.org](mailto:tbettencourt@jri.org)





# *Metrolina AIDS Project*

## *Caring for Families Program*

Charlotte, North Carolina

### **Program Snapshot**

Founded in 1985, the Metrolina AIDS Project (MAP) is a nonprofit organization and the Charlotte region's leading provider of comprehensive case management, support services, prevention education, and direct financial assistance to people living with HIV/AIDS. As a member of the United Way of Central Carolinas, MAP provides services on a sliding scale. All services are confidential. During the 2000–2001 fiscal year, MAP served 2,606 clients. Although consumers are actively engaged in all levels of program management and services, 7 of the 28 full- and part-time staff members hold the position of “service consumer.”

### **Caring for Families: Serving Charlotte and 12 North Carolina Counties**

Caring for Families is a program of the Metrolina AIDS Project that provides a regional network of education and support to women, children, youths, and families infected with or affected by HIV/AIDS.

#### **Program goals**

The Caring for Families network has four main goals:

- Develop and support comprehensive care, including primary care that is culturally competent, family-centered, and community-based
- Increase access to clinical trials and other research activities for women, children, youths, and families
- Reduce perinatal HIV transmission through outreach, comprehensive prenatal care, and increased provider education
- Enhance the involvement of those living with HIV/AIDS in the planning, implementation, and evaluation of HIV/AIDS services.

#### **Community collaboration**

Coordination, collaboration, expanded provider education, and consumer involvement are functions of the Caring for Families network. Seven agencies—MAP, Carolinas Medical Center, Duke University Medical Center, Charlotte Area Health Education Center, Gaston Family Health Services, Rowan County AIDS Task Force, and Iredell County's Fifth Street Ministries—are working with other service providers to foster

#### **Learn More About It!**

An innovative position within the MAP staffing pattern that lends itself to consumer staffing is that of service coordinator. Service coordinators bridge the gap between providers and people in need. They provide access to free confidential HIV testing, HIV/AIDS education, medical care, case management, transportation, food, shelter, clothing, childcare, pregnancy care, nutritional information, and emotional and spiritual support.



collaboration among other professionals, groups, associations, and practices.

### **Agapé Family Center**

As the cornerstone of the Caring for Families network, MAP's Agapé Family Center, which was established in 1994 and is located at the Holy Trinity Lutheran Church, provides respite day care for children from 6 weeks to 3 years of age. MAP offers transportation to and from the center, a weekly support group for women living with HIV/AIDS, an information resource center, and access to other regional service providers.

## **Organizational Readiness: From Policy to Practice**

MAP has created a legacy of integrating consumers at all levels in its program. Thus, consumers play key roles as board members, program administrators, and frontline staff members.

In addition to regular paid staff positions and membership on the board of directors, consumer involvement opportunities at MAP include:

- Part-time paid peer advocate/mentor positions (peer advocates identify others who are living with HIV but not engaged in medical care, educate consumers about services and research/clinical trial opportunities, and serve as advocates and mentors for others who are living with HIV disease)
- Volunteer peer advocate/mentor positions (duties are the same as part-time paid advocate/mentor positions)
- Membership on the consumer advisory board (members engage in program planning, advising, and evaluation)
- Membership on other community boards, including the Ryan White consortium, the Regional Care Planning Council, and other organizations
- General MAP volunteer positions (volunteers engage in public speaking, office work, fundraising, child care, etc.).

## **Policies to Support Organizational Philosophy**

MAP's strong commitment to consumer involvement in all aspects of the program is demonstrated by the visibility of consumers in many organizational roles. This commitment is also reflected in MAP's:

- Formal workplace policy on life-threatening diseases and disabilities
- Policy on consumer involvement

### **Voices of Experience**

"We have implemented fair and reasonable policies that allow for flexibility. ... The agency is accommodating, but communication (of variations from standard practice) is key."

— Executive Director, MAP



- Philosophy of “making sure we take care of staff members both physically and emotionally”
- Flexible approach to reasonable accommodations for all staff members, including those living with HIV/AIDS, which includes:
  - Documentation of time (“let us know where you are”)
  - Flextime when illness or medical appointments require absence from the workplace
  - A process to make up time taken away from work within the 2-week pay period
  - A process to allow for exceptions for extenuating circumstances
  - A formal communication process to ensure that no one is perceived as receiving special treatment
  - Short- and long-term disability insurance for staff members.

## Voices of Experience

“We encourage other programs to do a good assessment of the role consumers can play, to look at the value they bring to staff positions.”

— Program Coordinator, MAP

“Look at consumers as a resource to tap into, not window dressing.”

— Consumer Staff Member, MAP

## Recruiting Consumer Staff Members

MAP takes a multipronged approach to recruiting consumer staff members, including:

- Print media
- Web sites
- Word of mouth within the organization and community.

In all MAP employment advertisements, people living with HIV/AIDS are encouraged to apply. Regarding salaried staff positions, MAP does not hire an individual because he or she is a consumer; rather the organization seeks people who have the needed job skills or can gain these skills through training; hiring someone living with HIV/AIDS is considered a bonus.

### Recruiting peer advocates

The Peer Advocacy Program recruitment process differs in that only consumers can fill these positions. All MAP service recipients are informed of vacancies in this program. Additional announcements are made at program and community meetings, and job postings are circulated through mailings and e-mail distribution lists.

During interviews, candidates are informed about the diverse populations working at MAP and the agency's commitment to hiring consumers. Confidentiality standards are discussed and presented in writing. Some consumers disclose their status during the interview process; others disclose only after receiving an offer of employment.

In recruiting consumer staff members, it is essential to evaluate the consumer's readiness to be a service provider because individuals reach their point of “readiness” at different times in the process of integrating HIV status and must be comfortable in the disclosure process. Although reasonable accommodations can and must be made to support staff

members, consumers need to be informed that all employees have the same rights and responsibilities.

## Incentives

Incentives for recruiting consumer staff members include:

- Full medical coverage for employees working 30 or more hours per week (originally free of charge and more recently requiring a 10 percent contribution deducted from salary)
- Vacation benefits (2 weeks of vacation during the first year of employment, extending to 3 weeks in the third year of employment)
- Sick time (accrued monthly for a total of 10 sick days each year that can be carried over into the next year)
- Twelve paid holidays
- Access to short-term disability insurance and life insurance
- The comfort of working for an organization in which HIV disclosure is welcomed and supported.

## Hiring Consumer Staff Members

The hiring process for consumer staff members includes:

- Formal job descriptions are developed for all staff positions.
- Job descriptions are designed so that people living with HIV/AIDS can fill positions.
- All job descriptions are developed with consumer input.
- Consumers are encouraged to pursue promotion into management positions or are groomed for leadership by administrators.
- The program coordinator conducts job interviews, with input from either consumer staff members or board members who are service consumers. The inclusion of consumers during the interview process is critical because consumers are alert to subtle biases presented by candidates that may elude detection by nonconsumers.
- Encouraging managers to “think outside the box” and value the life experience of candidates who may lack formal academic preparation.

## Designing Compensation Packages

Compensation for regular staff positions at MAP is comparable to compensation offered for similar positions in other local agencies. Pay structure within the organization applies equally to both consumer and nonconsumer staff members, although the abiding organizational philosophy is “How can we make this work to maximize consumer involvement?”

### Voices of Experience

“Be clear about expectations and that exceptions will not be made.”

— Executive Director, MAP

### Voices of Experience

“We must move [consumers] into management and [prepare consumers for] leadership roles; otherwise, it's always 'us' and 'them.'...It is 'part of our role' to help consumers grow professionally.”

— Program Coordinator, MAP

“Select consumers who have a love for doing the work, provide them with the tools to be professionals, and be accommodating to their situations.”

— Consumer Staff Member, MAP

“Give people the opportunity [to work], allow them to make mistakes and learn, and be patient.”

— Consumer Staff Member, MAP



To this end, MAP looks at each employee's unique situation:

- Job sharing may be the answer for working parents or those managing medical problems.
- Individuals can also negotiate a shorter workweek or can be hired under contract rather than as a part-time employee to retain benefits.

One example of MAP's innovative compensation approach addresses the needs of some peer advocates. Because a full salary would jeopardize benefits available under Social Security Disability, an original plan to pay full salaries to peer advocates was revamped, reducing the compensation available and increasing the number of positions funded within the Peer Advocacy Program. All peer advocates are encouraged to discuss the potential impact on disability status with their case managers before applying for these positions. Creative thinking, attuned to the needs of consumers who must gain or retain health benefits, makes it possible for consumers to receive compensation for work performed and allows the organization to increase the number of positions available to consumers.

## Orientation of Consumer Staff Members

All new staff members receive 2 weeks of orientation that includes:

- Introduction to program staff in all departments
- Review of program policies and procedures with their direct supervisor
- "Shadowing" of other staff members who perform similar roles
- Initiation of weekly, individual clinical support with a clinic director not working at MAP to facilitate employee retention.

Of particular importance, MAP has developed a 16-week, two-phased orientation for peer advocates. This intensive orientation process requires flawless coordination and the investment of a great deal of time.

However, MAP's approach to orientation once again demonstrates respect for the skills and life experiences of adult learners.

## Designing Effective Training for Consumer Staff Members

In addition to in-house training, consumer staff members are required to attend regional training programs that address HIV, substance abuse, and mental health issues as well as North Carolina's case management training program. Although these training opportunities are offered to all incoming staff members regardless of HIV status, consumer staff members may require additional support in processing the information presented because aspects of the training may hit particularly close to home.

### Voices of Experience

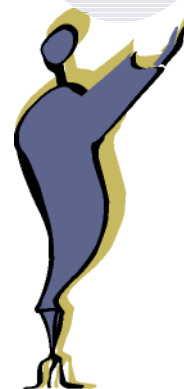
"I was doing this before receiving money, [although the money reflects a] confidence in you. If we don't stand up for ourselves, who will?"

— Consumer Staff Member, MAP

### Learn More About It!

MAP's 16-week peer advocate orientation curriculum:

- Phase 1 includes group trainings and individual meetings that focus on personal skills that help develop empowerment, bonding, self-esteem, team-building skills, trust, leadership, HIV-related psychosocial knowledge, boundaries, and comfort with self-disclosure.
- Phase 2 includes professional skills development; education on the Ryan White CARE Act, Ryan White funding and services, HIV research and clinical trials, AIDS prevention, and HIV treatment; conducting outreach and case finding; facilitating effective meetings; mentoring and coaching; and an overview of available resources and services for people living with HIV/AIDS.





MAP also uses training to support the program's commitment to the advancement of consumer staff members to administrative and executive positions. As the executive director noted, "It's about empowerment, not enabling and about reinforcing the 'normalization' of consumers filling staff positions and the program's philosophy of pushing all staff members—including consumer staff—to maximize their potential."

## Supervising and Supporting Consumer Staff Members

Consumer staff members have averaged 3 years or more of employment with MAP. In fact, consumer staff members have generally enjoyed greater longevity with the organization than nonconsumer staff members. They hold a variety of administrative and staff positions in program operations and service delivery. The staff is diverse with regard to gender, age, race, and ethnicity, as well as the fact that some have identified themselves as being in recovery from substance use or as having a history of severe mental illness.

The fact that consumers hold high-level positions in the organization and have been promoted into those positions demonstrates a model of success for consumer employees. Many consumer staff members describe increased responsibility within their current positions or promotions during their tenure with MAP.

The program coordinator, with the administrative coordinator offering backup at times when the program coordinator is not on site, supervises all Title IV staff members individually. The administrative coordinator position was created to relieve the program coordinator from fiscal management of the program, thereby allowing her to focus on the training and support of staff members. Case managers cannot supervise consumer staff members for whom they provide services. The executive director provides additional support when his services are requested in this area. Other training/supervisory experiences are offered through a monthly Title II case staffing and a monthly internal case conference.

In addition to this extensive programmatic support, all "client-involved" staff members have weekly individual supervision with the clinical services director, who is not funded through Title IV. These meetings explore job performance and job needs. The supervisor identifies stressors, offers strategies for reducing the impact of these stressors, and generally attends to the professional and personal growth of staff members. One consumer staff member talked about identifying with clients and their situations ("I feel it more than my co-workers.") and benefiting from the opportunity to talk this through with the clinical services director.

Peer advocates also receive individual supervision from the program coordinator. All peer advocates who were interviewed experienced this supervisory relationship as deeply personal and sustaining. One observed that "the staff had to help me fix me" before she was capable of being effective in her role. Another remarked that she could always call her

### Voices of Experience

"We help staff to stay professional in their role, be it someone living with HIV or in recovery from substance use."

— Program Coordinator, MAP

(This training) "Has taught me to separate my personal life from the workplace."

— Peer Advocate, MAP

"Consumers might benefit from specific training in such areas as computer literacy, time management, and organizational skills to be more effective in their roles."

— Consumer Staff Member, MAP

"There's a need for cultural competency training for all staff and training in grief. Would be useful in my work."

— Peer Advocate, MAP





supervisor: “She’s never too busy for me. We go through things together.”

MAP administrators emphasize the need for programs to invest in both clinical and administrative supervision and the importance of offering individual supervisory sessions in addition to group supervision. They emphasize the need to create a safe and supportive environment, to “be clear about equal offerings to all staff,” to articulate an organizational commitment to offering opportunities for growth as well as the support and encouragement staff members need to move out of his or her “comfort zone,” take on more responsibility, realize his or her full potential, and move further along in the structure of the organization. Consumer staff members benefit from a deep personal connection with his or her supervisor, someone they are able to count on to facilitate the resolution of professional—as well as personal—difficulties.

## Creating an Organizational Climate of Support

The organizational climate created by MAP clearly exemplifies a workplace that has strategically assessed how and in what roles consumers can contribute to the program’s goals; designed staff positions that allow the program to provide the best possible services to their clients; created strong supervision and support for consumer staff members; invested in extensive, skill-enhancing training; and created a staffing structure to allow consumer staff members to grow professionally and be promoted within the organization.

### Voices of Experience

Consumer staff members gave the following reasons for staying with MAP:

- “Job satisfaction”
- “A low-key work atmosphere”
- “Looking forward to going to work each morning”
- “Getting the low-down on upcoming [medical treatments]”
- “Genuine concern from supervisors”
- “Working with wonderful, patient people”
- “Wanting to see someone get to the other side [of an emotional crisis]”
- “Making a difference in someone’s life,” “having the chance to give of myself”
- “[Being able to] give back what I have been taught”
- “Feeling needed”
- “Having the chance to give something back”
- “Working for an agency that gives life back to people”
- “Gaining more compassion for substance abusers”
- “[Seeing] people find hope.”
- As one peer advocate noted, “I learn something every day I come here.”



## Highlights of Program Policies and Other Materials

Policies and Other Materials	Specific Program Examples
Job descriptions	Service Coordinator Consumer Coordinator Peer Advocate Team Member
Policy on consumer involvement	Consumer involvement policy
Written confidentiality policy	Written confidentiality policies
Written expectations of consumer/employee agreement	Contractor agreement
Orientation/training materials	Orientation guide for consumers (in progress)

### Program Contact

For further information about the Metrolina AIDS Project, contact:

Faye Marshall

Program Director

704-372-4747

[fmarshall@metrolinaaidsproject.org](mailto:fmarshall@metrolinaaidsproject.org)



# *University of California, San Diego Mother, Child, and Adolescent HIV Program*

San Diego, California

## **Program Snapshot**

The University of California, San Diego, Mother, Child, and Adolescent HIV Program (MCAHP) provides comprehensive HIV care to pregnant women, mothers, children, and teens. Since its inception in 1988, MCAHP—which became a Title IV program in 1996—has emphasized prevention of HIV transmission from mother to child. Program clients learn about all of the various options that can help reduce maternal–infant HIV transmission.

### **Team approach**

A multidisciplinary team of 27 HIV specialists, including four consumer staff members, assists families with complex psychosocial needs. The team also manages youth outreach and adolescent health care programs. Most of MCAHP’s clients are Latina and African-American. Because so many of MCAHP’s clients speak only Spanish, most of the program’s staff members are bilingual.

### **Community collaboration**

As a large university and medical center–based organization, MCAHP’s emphasis has been to support community-based organizations. Thus, it has never competed with them for funding. MCAHP has initiated and participated in a number of important community collaborations. For example, one of MCAHP’s consumer staff members is assigned to Christy’s Place, a community-based organization serving African-American women and their children. MCAHP developed a San Diego County–wide training program for case managers and consumer peer advocates. Because MCAHP is located close to the Mexican border, it has partnered with Tijuana’s General Hospital to provide services to clients.

### **Notable Achievement**

MCAHP has achieved a transmission rate of less than 2 percent and since December 1994 has not had an HIV transmission among women in its care.

## Organizational Readiness: From Policy to Practice

MCAHP's commitment to hiring consumer staff members is founded on the following beliefs:

- Consumers add value to the program in a way that nonconsumer staff members cannot.
- Consumer staff members' contributions equal those of any other professional staff person.
- Consumers can benefit from working as program staff members.

Current consumer staff members work as patient, family, and youth advocates. To maximize employment opportunities, MCAHP offers various work options. Youth advocates also coordinate outreach activities. One consumer staff member works half of the time as a patient advocate and as an administrative assistant the other half. Another patient advocate works from an African-American community-based organization that provides onsite childcare. Other consumer involvement opportunities include working on short-term projects and special events.

To facilitate integration of consumer staff members, MCAHP found it crucial to obtain rather than assume staff buy-in and to research what university and medical center systems requirements had to be negotiated to successfully incorporate consumer staff members into the program.

## Policies to Support Program Philosophy

MCAHP highly values families and has workplace policies that support a healthy balance between work and life for all of its employees. These policies include:

- Flextime to accommodate school, commuting, health, and family needs and responsibilities. Flexible hours benefit the program by making it possible to operate longer hours, which better meets clients' needs.
- As University of California, San Diego, employees, consumer staff members can work half-time and still receive immediate health care benefits despite preexisting conditions.
- Formal and informal staff members support and assist with stress and time management to achieve a healthy work-life balance.
- Learning through trial and error as equal partners.
- Allowing job responsibilities to evolve over time to better fit consumer staff member and program needs with consumer advocates participating in the reevaluation and design of their job descriptions.
- Client payment voucher policy for short-term/temporary work projects.

### Learn More About It!

MCAHP offers the following tips for preparing an organization for consumer staff members:

- Involve program staff members with consumer staff job description development. This approach will give you a better idea of staff concerns and an opportunity for everyone to discuss them, anticipate challenges, come up with better solutions, and in the process, obtain more genuine buy-in.
- Try to anticipate implementation issues and develop policies and procedures to handle them as soon as possible.
- Educate all program and organization staff members on consumer staff member roles and responsibilities, how to access consumer staff member services, and how they add value to the program/organization before consumer staff members arrive on site.
- Be sure that your organization's systems can provide development and/or promotional opportunities and comparable salary increases for consumer staff members.



## Recruiting Consumers

Because MCAHP is a Title IV program, only Title IV consumers can fill the patient advocate positions. For this reason, general advertising through traditional vehicles was ineffective, yielding primarily non-HIV impacted or non-Title IV applicants. MCAHP obtained more effective results by recruiting among clinic patients and within the local Title IV HIV community. The greatest challenge has been recruiting consumers who are willing to disclose their HIV status and who are fluent in Spanish and English.

## Incentives

Recruitment incentives for consumer staff members include:

- Full benefits (medical, dental, vision, retirement, sick days, etc.) for half- to full-time work
- No physical or medical exam required for employment
- Full health benefits for those with preexisting conditions
- Flexible hours
- Employee Assistance Program
- Through the university, local theme park discounts
- Working in an organization that values and supports people living with HIV
- Working in a medical center that specializes in HIV and thus having even greater access to its resources, including clinical trials.

For short-term projects such as health fairs or seasonal office work, MCAHP provides vouchers that clients can use to purchase necessities of life. This approach allows clients who are undocumented and/or unable to work full-time to acquire some compensated job experience without adversely affecting their benefits or residence status.

## Hiring Consumer Staff Members

The hiring process includes:

- Formal job descriptions, approved by the university's human resources department
- Job descriptions designed so that people with HIV or those with HIV-positive children can successfully fill them
- Consumer input into the development and evolution of their job descriptions
- Waived degree requirements for consumer advocate positions
- Staff and program consumer participation in the hiring process

### Voices of Experience

"Consumers have special skills and life experiences that make them uniquely qualified to be client advocates."

— Program Coordinator,  
MCAHP

"Christy's Place has onsite child care. I can be with my kids, and when clients see me at work with them, it gives them hope. I'm role modeling where they want to be."

— Patient Advocate,  
MCAHP

### Voices of Experience

"Don't be afraid to ask for help. Let others know when you're uncomfortable with something and don't be afraid to give feedback to the program. That's one of the reasons they hired us, to help improve the program from the inside."

— Client Advocate,  
MCAHP



- Provision of clear expectations, methods of accountability, and development opportunities.

## Designing Compensation Packages

Because MCAHP is part of the University of California (UC) system, it uses their pay scale and human resources infrastructure. Consumer advocate salaries are at the higher end of their job classification level and thus are very competitive. One of the disadvantages of the UC system, for consumer staff members with longer tenure, is the need to take on significantly more responsibility to move into higher-level job classifications to receive greater compensation.

Because the UC system makes part-time employment difficult and many consumers cannot work full-time, MCAHP created an innovative “necessities of life” voucher system. This system provides incentives and compensation for consumer participation in short-term projects. The vouchers do not interfere with consumer benefits and can be used by undocumented patients.

## Orientation of Consumer Staff Members

Consumer advocates go through the same standardized orientation that other employees do, but with some customization depending on specific job requirements. Orientation for all employees includes:

- Half-day UC employee orientation that covers UC benefits, policies, and procedures
- Half-day orientation to the UC San Diego Medical Center
- MCAHP orientation that includes
  - Administrative policies and procedures
  - Program history, services, and staff
  - Review of job responsibilities with direct supervisor
  - “Interviews” and observation with key staff members that enables consumer new hires to build relationships and discuss how their roles and responsibilities interface with other staff members
- Community and Web resources.

Because MCAHP hires consumer staff members throughout the year, new staff members develop their individual orientation schedule with their supervisor. Using an orientation checklist of essential items to be addressed, new staff members are required to complete all checklist items within 1 month of their “start date.”

### Learn More About It!

MCAHP’s voucher program includes the following:

- MCAHP purchases or obtains donated vouchers or “gift certificates” from Wal Mart, Target, and local grocery stores.
- Because they can only be used for necessities-of-life items, voucher purchases are considered as program participant costs—as approved by the Health Resources and Services Administration.
- Policies and procedures are in place for voucher distribution and accountability.
- Vouchers are equivalent to \$10 per hour of work time and/or work-related expenses.
- Consumers can earn vouchers by participating in the following activities:
  - Program consultation
  - Document and materials review
  - Office support for mailings, brochures, and conferences
  - Presentations at schools, health fairs, and other community gatherings
  - Participation in focus groups, community planning activities, and Ryan White CARE Act partnership meetings.





## Designing Effective Training for Consumer Staff Members

The San Diego County Office of AIDS Coordination requires that all case workers and case managers who work with HIV-affected clients complete a training program that minimally addresses the following issues:

- Peer advocate counseling skills and self-care
- Setting appropriate boundaries
- Coordinating peer advocacy and case management
- Client rights and responsibilities
- Client interviewing and documentation
- Ethics and professional conduct, confidentiality, and contract compliance
- Mental health, chemical dependency, and crisis intervention
- Permanency planning and foster care/adoption
- Cultural diversity, women, and HIV
- Local resources, accessing benefits, and legal issues
- Secondary prevention.

In addition to the San Diego County training, all new staff members complete a training session that addresses the Health Insurance Portability and Accountability Act, as well as monthly in-service training sessions. The MCAHP staff generates topics for these in-service training sessions. MCAHP encourages and supports consumer staff member participation in trainings offered by the local community as well as participation in regional and national conferences. The program arranges for staff members to attend training programs during work hours, provides financial assistance as resources allow, and helps staff members find and apply for conference scholarships.

## Supervising and Supporting Consumer Staff Members

MCAHP supervisors are licensed clinical social workers that also serve as client case managers. Because MCAHP does not have the staffing or financial resources to hire supervisors who do not also provide direct services, both supervisors and consumer staff members need to set and maintain very clear and consistent boundaries to successfully manage their inevitable dual relationships.

To supervise unlicensed social workers such as consumer staff members, MCAHP supervisors must complete a series of social work supervision training sessions required by the State of California. They apply the skills learned in these training sessions to the supervision of consumer staff members. As case managers, MCAHP supervisors are required to

### Voices of Experience

"Sending staff to local and out-of-area conferences is really helpful. They bring back new perspectives and can network with peers in other programs. We let them know that we value the new information and perspectives they bring back."

— Program Coordinator,  
MCAHP

"Going to outside conferences gave me the chance to be with other people like me. It was so empowering, and it helped me better define and do my job."

— Youth Advocate,  
MCAHP

"I like that I can say 'I don't know how to do this,' and they'll say 'Maybe other people need to know this too, and we can have an in-service about it.' I've learned so many new skills, and it's given me more direction and purpose in my life. I'm able to give back more and make a difference."

— Client Advocate,  
MCAHP

### Voices of Experience

"My supervisor gives me time to learn and think about things, make improvements. She trusts me to do my job. When I feel overloaded, the team chips in. If they notice I'm burning out, they encourage me to take time off. They give me flexible hours so I can do school and then increase my hours over the summer."

— Youth Advocate,  
MCAHP





complete the same county case management/peer advocate training that their consumer staff members must complete. The results of the training are evident in the comments of consumer staff members.

Supervision is an ongoing process, and two-way feedback is crucial to its effectiveness. Consumer staff members note that their ability to openly and honestly discuss and work out their differences with their supervisors strengthens the supervisor/staff relationship and leads to better services for their clients. Consumer staff members voice their appreciation for their supervisors' assistance with stress management and helping them achieve a healthy balance between work and life.

### **Provide critical timely feedback**

To ensure timely feedback, consumer advocates have monthly performance evaluations and “check-in” sessions during their first 3 months of employment. Program staff members report “great results” since MCHAP formalized this process. Consumer staff members quickly learned what was expected of them, and this accelerated learning process resulted in rapid job performance improvements and integration of consumer staff members into all aspects of the program. To support the feedback process, MCHAP designed a “patient satisfaction form” for clients to complete about their “client advocate” (consumer staff members).

### **Create an organizational climate of support**

In addition to the organizational support systems—training, supervision, policies and procedures, benefits, and flextime—that MCHAP provides for its consumer staff members, there is an organizational culture that strongly believes in the value of consumer staff members and creates a work environment that supports and mentors them both formally and informally on a daily basis. Consumer staff members express their ability to be a genuine part of a team that “looks out for me.” MCHAP’s staff practices what it preaches to facilitate a healthy balance between work and life for everyone. MCHAP management truly understands and responds to the changing needs of its employees without sacrificing job standards. As the program coordinator says, “My job is finding ways to grow and accommodate staff needs and get the system to respond.”

### **Learn More About It!**

Supervision tips from MCAHP include the following:

- Create a safe environment where you can have open two-way feedback. Feedback needs to be regular and timely. Encourage consumer staff members to give you feedback, too.
- Teach consumer staff members how to use supervision. This is especially important if they have not had any or little job experience.
- Provide guidance on setting limits. Let consumer staff members know why it is important to them and their patients not to be overly involved and available.
- Help clarify roles and responsibilities. This includes understanding, setting, and maintaining clear boundaries. Be clear what crossing the line looks like and clearly describe the consequences to the client, the client advocate, and the program.
- If you occupy dual roles, when switching roles from service provider to supervisor, be clear and explicit about each role switch and have them do likewise.
- Make sure you build in enough time to provide good supervision. Most people underestimate the time required, especially in the beginning.
- Focus on building consumer staff members' competency. Start where they are and build on their existing strengths and assets.
- Be professional and hold consumer staff members accountable, just like you would other staff members.



## Highlights of Program Policies and Other Materials

Policies and Other Materials	Specific Program Examples
Job descriptions	Client Advocate Outreach Coordinator
Policy on consumer involvement	Client voucher policy and signature form
Written confidentiality policy	Confidentiality statement
Written expectations of consumer/employee agreement	Written expectations of consumer
Orientation/training materials	Orientation for program personnel Case management–peer advocacy basic initial training agenda
Use of satisfaction/feedback surveys	Consumer feedback surveys

### Program Contact

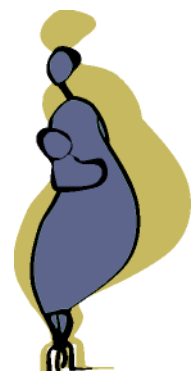
For further information about the University of California, San Diego, Mother, Child, and Adolescent HIV Program, contact:

Mary Caffery

Program Coordinator

619-543-8080, extension 236

[mcaffery@ucsd.edu](mailto:mcaffery@ucsd.edu)





## On-Site Protocol

**Purpose of project.** The Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) has funded Circle Solutions, Inc. (Circle), to develop *Guide to Best Practices in the Employment of Consumer Staff in Title IV Ryan White Programs*. The purpose of the guide is to describe the experiences of Title IV programs that have fostered the engagement of consumers in all aspects of program design, implementation and evaluation.

**Research methods.** Circle has proposed a three-pronged research methodology to identify effective organizational strategies to recruit, hire, supervise, train and mentor consumer staff. During phase one, Circle reviewed existing grantee applications and progress reports to identify 30 Title IV programs with substantial experience in the employment of consumer staff. The proposed sample of 30 programs was vetted by HAB.

During phase two of the project, Circle staff conducted extensive telephone interviews with the Program Directors/Coordinators of the select 30 Title IV programs to capture comprehensive information about the processes these programs used to successfully recruit, hire, train, supervise and retain consumer staff. During these interviews, we focused on specific strategies that programs utilized to address such workplace issues as role boundaries, design of job descriptions, compensation and benefits, confidentiality of medical status, and special issues related to employing youth.

During phase three, Circle staff and consultants will conduct 2-day site visits to three Title IV programs, which may, based on the above telephone interviews, demonstrate model organizational strategies to engage consumer staff at all levels within Title IV programs. The purpose of the site visits is to gather more in-depth information about the organizational/workplace strategies that have been successful in recruiting, hiring, supervising, training and mentoring consumer staff. The information will be used to demonstrate how “best practices” can be implemented by a range of Title IV programs.<sup>3</sup>

**On-site protocol.** Circle plans to conduct up to a 2-day site visit at each of the three sites. Circle’s Project Director and two Senior Technical Advisors will each visit one site. During the site visit, we anticipate conducting the following activities:

- Meeting with the Title IV Program Director/Coordinator (approximately 1–1.5 hours)
- Meeting with Organizational Director (if different from Title IV Program Director and as designated by Program Director) (approximately 30–45 minutes)
- Meeting with Supervisors of Consumers (approximately 1–1.5 hours)
- Meeting with Consumer Coordinator (approximately 1–1.5 hours)
- Focus Group with Consumer Staff (approximately 2 hours)

---

<sup>3</sup> The sites we have identified represent a cross-section of geographic locations, include both adult and youth programs and provide services through different venues, including a University-based program and private, non-profit organizations.

Review of Workplace Policies and Sample Materials addressing consumer/staff training, job descriptions and benefit information, confidentiality protocols, supervisory training, recruitment materials and any other materials as designated by the Program Director which may be helpful to other Title IV programs as they seek to create organizational strategies to fully engage consumer staff in all aspects of the Title IV program.

Since each of the selected sites is unique, the on-site protocol is intended only as a guide to the on-site discussions and observations. Circle will work with each of the program Directors/Coordinators to identify the appropriate participants for the on-site interviews as well as the review of the most appropriate program documents.

In addition, the attached describes the identity protections for consumer staff and the reporting of the data from the consumer focus group meeting.

## Discussion Guide for Ryan White Title IV Program Directors/Coordinators

**Title IV Program** \_\_\_\_\_

Program Director/Coordinator (Interviewee):

\_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Email: \_\_\_\_\_

Circle Interviewer: \_\_\_\_\_

Date: \_\_\_\_\_

### Contact Notes:

### Introduction

The Program Coordinator should have received a fax introducing the Best Practices in the Employment of Consumers Project. Confirm and elaborate on project as necessary. Explain the operational definition we are using for “consumer”: a parent, guardian (legal or de facto) or youth who is or has been a consumer of Title IV services.

For the purposes of this research project, a program that only has an HIV-infected staff person who is NOT a parent, guardian, or youth does not qualify as having consumer staff.

### I. Background of Consumer Staff Involvement

1. How many staff persons in your program are or have been consumers of Title IV HIV-related services?
2. In what capacities (job titles and responsibilities) are consumers employed?
3. How long have these consumers been employed? (Probe for how long the average consumer employee stay on the job—try to establish attrition rates.)

4. How have the roles/responsibilities of consumer staff evolved over time?
5. What roles would you like consumers to take on that they do not currently hold?
6. In your estimation, how integrated are consumer staff in the entire program? (Probe for the range of services the program offers and whether consumers are engaged in all aspects of program implementation.)
7. Are consumers regularly involved in staff meetings? To what degree? Are there organizational meetings at which consumers are NOT involved? Why?

**Recruitment of Consumers**

8. How did/do you recruit your consumer staff? (Probe for recruiting strategies—how is program staff (including consumer staff involved)?
9. What have been the challenges to recruiting consumers?
10. What specific steps has the program taken to address these challenges?
11. What types of flexibility and incentives are offered? (full-time versus part-time, transportation, childcare, etc). Have these incentives been used? What challenges are associated with these incentives? Do the recruitment materials talk about these incentives?
12. Do you have recruitment materials you could share with us?



13. From your experience, what advice can you share with other Title IV programs that want to successfully recruit consumer staff?

#### **Hiring of Consumers**

14. Does your program have formal job descriptions for consumer staff positions? Will the program share its job descriptions with us and with other Title IV programs? How were these job descriptions developed (e.g. who had input in the development of the job descriptions)?  
Probe for:

- Have they been revised? What were/are the challenges for developing job descriptions? What specific steps did the program take to overcome these challenges?

15. Who is involved in the hiring process for consumer staff? Please describe this process.

16. What can you share with other Title IV programs regarding the hiring process of consumer staff?

#### **Compensation of Consumers**

17. How is compensation for consumer staff determined? Do you believe the compensation is competitive for similar professional services in other agencies?

Probe for:

- What have been the challenges in designing a compensation and benefits package for consumer staff? How has the program addressed these challenges? How often are compensation issues reviewed and revised?

18. What can you share with others regarding compensation of consumer staff?

#### **Orientation, Training, and Support of Consumer Staff**

19. What is the orientation process for new consumer staff?

Probe for:

- Length of orientation. How program employees are involved in the orientation. Do they assess the effectiveness of the orientation process? What have been the challenges to designing and implementing their orientation process? Has the program reviewed and revised its orientation process?

20. What is the orientation process for other program staff (Probe for how does the program prepare other staff for the arrival of consumers)?
21. What can you share with others regarding orientation of consumer staff and other program staff?
22. What training is offered to consumer staff?  
Probe for:
- How often is the training offered? Who conducts the training? What “outside” training opportunities are afforded consumer staff? How is training financed/supported by the program?
  - How does the program assess the training needs of employees, including consumer staff? What are the greatest training needs? How have those been addressed? What are the challenges to training? What steps has the program taken to address these challenges?
23. What advice can you share with others regarding training of consumer staff?
24. What strategies has the program implemented to retain consumer staff?
25. What have been the challenges to the promotion of consumers? What steps has the program taken to facilitate promotion of consumer staff?
26. How does the program support consumer staff? What kind of support do consumers need? What are the challenges to providing adequate support services?
27. Where do consumer staff go for their treatment (Probe: Do consumers use the services of the Program or do they use other agencies for their services? Also probe for the organization’s philosophy about consumers using their services.)

**Supervision of Consumer Staff**

28. Describe how consumer staff are supervised? Who supervises consumer staff? Is their performance reviewed? What are challenges to supervising consumer staff? What steps are taken to resolve these challenges?
29. What types of management/supervision training is provided for managers who supervise consumers?
30. What advice do you have for other programs regarding supervising consumer staff?

**Organizational Readiness: Planning for Consumers in the Workplace**

31. Does the program have a formal workplace HIV policy?  
Probe for:
- When was it developed? What are its components? Which component(s) have been the most challenging to implement? How has the program addressed these challenges?
32. Does the program have confidentiality policies? What are they? What have been the challenges in implementing confidentiality policies? What strategies has the Program employed to ensure confidentiality?
33. What types of requests for “reasonable accommodations” has the program experienced?  
How has the program responded to requested accommodations?  
Probe for:
- What challenges did the program face in attempting to accommodate employees? How has the program addressed these challenges?
34. Who are the primary customers of the program’s services? What is their ethnic makeup?
35. To what extent do consumer staff reflect the cultural/racial makeup of program customers? What have been challenges faced by consumer staff in this area? How does the program prepare consumer staff to deliver culturally appropriate services?

36. What advice can you share with other programs regarding consumer staff and their role in delivering culturally appropriate services?

**Special Issues Related to Youth Services (in addition to the discussion issues above, youth programs will be asked the following)**

37. What are the special considerations when employing minors?

Probe for:

- What have been the greatest challenges in employing consumer youth, particularly in the areas of case management, youth expectations, and confidentiality? What steps has the program taken to address these challenges?

38. What advice do you have for other programs in terms of using consumer youth?

## Discussion Guide for Ryan White Title IV Consumer Staff

**Title IV Program:** \_\_\_\_\_

Code Number: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Email of Program Director/Coordinator: \_\_\_\_\_

Interviewer: \_\_\_\_\_ Date: \_\_\_\_\_

### **Contact Notes:**

### **Introduction**

The Ryan White Title IV staff should have received a memo describing the purpose of the project and their role in the interviews. Copies of the discussion guide should have been sent to the Program Director/Coordinator for dissemination among all staff participating in the discussions. Consent forms should be signed and returned to Circle Solutions.

At the start of the discussion, thank participants and reiterate that the information the consumer will provide will be confidential. We will not disclose specific names or comments. But report their information only in summary form. Also, remind the consumer staff interviewee that their participation is totally voluntary.

### **I. Background of Consumer Staff Involvement**

1. What do you do/what are your responsibilities at the program?
2. How long have you worked for the program?
3. Have your roles/responsibilities of changed over time? If yes, please tell us how your responsibilities have changed.
4. What do you think consumer staff can do at the program that they do not do now?

## **II. Challenges and Benefits**

5. What have been the challenges you have faced as you became a staff member of the program (Probe for issues such as role boundaries, work expectations, work schedule, compensation and medical/health care benefits, child care issues)?
6. How has the program help you to overcome these challenges? What more can the program do to help with the challenges?
7. What have been the benefits of working with the program? What makes you stay with your job?
8. What advice would you give to other Ryan White programs that wish to recruit and employ consumer staff?

## **III. Orientation, Training and Support of Consumer Staff**

9. How has the program prepared you for your new role as a staff member? (Type and length of orientation, types of training that consumers receive.)
10. How does the program support you and your needs as a consumer staff person?
11. How "accepted" are you by other program staff? (Probe for what steps the program has taken to welcome and integrate consumers as staff).
12. Please tell us how you work with your supervisor. (Probe for: do consumer staff feel that they receive adequate and quality supervision; do they have concerns about the level of supervision they receive; what supervision would they need that they are not getting now.
13. What advice do you have for other programs as they develop orientation, training, supervision, and support strategies for consumer staff.

## **IV. Special Issues Related to Youth Services (In addition to the discussion issues above, youth programs will be asked the following)**

14. What have been the greatest challenges to working in a youth program? What have been your expectations and how have your expectations been met/or changed?
15. What advice do you have for other programs in terms of using consumer youth?

